

FEEDBACK FROM THE FIELD

Identifying Special-Needs Households That Need Assistance for Emergency Planning

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State governments are increasingly requiring state and local emergency management offices to maintain lists of persons with special needs who may require assistance in disaster situations. In addition, federal courts are beginning to apply the Americans with Disabilities Act to emergency planning. This study characterizes special-needs households that are located in the vicinity of a chemical weapons storage site in Alabama. For this study, a special-needs household is defined as a residence having at least one person with physical or mental problems, a transportation dependence, or a child who is home alone at times and requires assistance from outside the family or current circle of relatives, friends, and neighbors to take specific protective actions. The special-needs households were identified through a myriad of collection methods, including random sampling, saturation mailing/self-registration, targeted distribution/self-registration, agency and support provider lists, and referrals. Attitudes toward specific protective actions and an assessment of the ability of the special-needs household to take those actions were also sought out. Approximately 9 percent of the community's households were identified as containing persons with special needs who require assistance during emergencies. The study also identified the highly perishable nature

of special-needs population records maintained by emergency management agencies. During a data verification process conducted 3 months after the data collection effort concluded, almost half of the previously identified 3,294 individuals with special needs had their situation change or could not be reached for verification. Concurrently, 1,090 new persons with special needs identified themselves as needing assistance. Recommendations are made to the emergency planning community for addressing the support needs of special populations.

Many states are now requiring local emergency management offices to obtain and update the registration of persons with special needs who may need assistance in the event of a disaster (Drabek and Hoetmer 1991). This concern for emergency preparedness for the elderly and disabled was echoed recently in testimony before the Senate (United States Senate, Special Committee on Aging 2002) and in the Disaster Mobilization Initiative being carried out by the National Organization on Disability (2002). The methods currently used to identify and assess the special-needs population vary by community and in their degree of success. To ensure a successful identification process, emergency management planners need to obtain a profile of the special-needs population that would then serve as a base case for measuring identification procedures and updating lists, as well as responding to needs for assistance.

Concern about emergency planning for those with special needs may become more relevant as federal courts begin to apply the Americans with Disabilities Act (ADA) (P.L. No. 101-336) to emergency planning. Among its requirements, the ADA states:

No qualified individual with a disability shall, by reason of such disability, be excluded from participation in or be denied the benefits of the services, programs, or activities of a public entity or be subjected to discrimination by any such entity. (42 U.S.C. section 12132).

In the case of *Shirey v. City of Alexandria School Board* (229 F.3d 1143 [4th Cir. 2000], 2000 U.S. App. LEXIS 21236) (*per curiam*), the Court of Appeals for the Fourth Circuit decided whether the defendant school board had violated the ADA in 1996 when it left Cady Shirey, a disabled middle school student, inside the school for seventy minutes with another disabled student and a responsible adult while the rest of the students were evacuated in response to a (false) bomb threat. After ana-

lyzing the ADA and a similar section of the Rehabilitation Act, the court decided that:

The correct inquiry is simply whether the School Board's actions have denied Cady and other disabled students access to the program in question—namely, safe evacuation from school buildings during an emergency.

Finding that "the School Board had no reasonable plan in place to evacuate disabled children from school buildings during an emergency" at the time of the bomb scare, the court held that the school board had violated the ADA. To the extent that *Shirey* is a harbinger of future ADA litigation, it will be essential for emergency planners to improve their understanding of the characteristics of disabled members of the special-needs populations in their communities.

Only minimal research has been conducted to study preparedness and response planning for persons with disabilities in natural, technological, and terrorism disaster situations, although these areas are becoming increasingly important (Tierney, Lindell, and Perry 2001). While researchers have not fully profiled the vulnerable special-needs population or tested data collection methods for their identification, they are beginning to reach some understanding of the decision-making process and response actions of special-needs population segments. Specifically, researchers have focused on the elderly (Gladwin and Peacock 1997; Lindell and Perry 1997; Morrow 1999); gender type (Fothergill 1996; Enarson 1998; Mulilis 1999); ethnicity and minority status (Lindell and Perry 1992; Drabek 1986; Riad, Norris, and Ruback 1999; Fothergill, Maestas, and DeRouen-Darlington 1999); poor households (Blaikie et al. 1994); female head-of-households (Morrow 1999); and women and children (Myers 1994). Some general characterizations have depicted the special-needs population as being isolated in social and geographic space, primarily because they have fewer opportunities for community interaction, social networks, and personal acquaintances (Penninx et al. 1999; Petrowsky 1976; Greenbaum and Greenbaum 1985; Campbell, Marsden, and Hulbert 1986; Moore 1990; Schensul et al. 1999).

The Alabama Emergency Management Agency (AEMA), supporting the Chemical Stockpile Emergency Preparedness Program (CSEPP), recently provided funds to conduct a public safety survey using multiple data collection methods to identify and characterize the special-needs population residing within an area, called the Immediate

Response Zone (IRZ), extending approximately 8 to 11 miles from the Anniston Army Depot where chemical weapons are stockpiled. For this survey, a special-needs household was defined as a residence having at least one person with physical or medical problems, a transportation dependence, or a child who is home alone at times (i.e., a "latch-key kid"). These persons would need assistance from outside the family or current circle of relatives, friends, and neighbors to take protective actions during an emergency situation. A follow-up verification of records and a new survey conducted a year later provided additional information regarding the perishable nature of the data. At the same time, information was gathered for developing and implementing a continual process for identifying individuals with special needs. By using Special Population Planner (SPP) software developed by Argonne National Laboratory, planners were able to geocode the addresses of persons with special needs and map their personal data for planning purposes. SPP is a county-level emergency planning and response system with detailed, geographically referenced information about populations, facilities, potential hazard events, resources, infrastructure, and traffic access/control points. Its on-screen maps present data in a format that is easily and quickly understood.

A Case Study: Identifying and Characterizing a Special-Needs Population

The area studied is located in northeastern Alabama, approximately 50 miles east of Birmingham and 100 miles west of Atlanta, Georgia. The IRZ, containing approximately 31,000 households with roughly 75,000 persons, would be the first emergency planning zone affected by a release of a heavy concentration of chemical warfare agents from the depot with a less than one hour response time under typical weather conditions (Federal Emergency Management Agency 1996). Due to the potential of very limited warning and population response times, special effort is placed on identifying at-risk individuals with special needs. The major population center is the City of Anniston, located east of the depot.

Prior to this effort, information on special-needs households was collected through an annual self-registration process consisting of returning a postcard included in an emergency preparedness calendar provided to the citizens of one county or by calling a telephone number provided in a similar calendar in another county. The postcard method identified 632 persons (approximately 400 in the IRZ) over a

five-year period, whereas the telephone method identified one person with special needs.

Identification Methods

Five identification methods were used to collect data on individuals with special needs in the IRZ: a random-sample survey, saturation mailing of self-registration packets, targeted distribution of self-registration packets, list acquisition, and referrals. These methods, or variations of them, can be used to identify individuals with special needs in rural and urban areas, small and large geographic areas, by in-house staff or contracted, and for different types of fixed facility, mobile, physical feature, weather-related, or random weapons of mass destruction threats. For example, instead of a saturation mailing, a designated area could be fairly well covered through inserts in newspapers or utility bill envelopes or the placement of mail-back questionnaire coupons in local newspapers. Instead of a targeted mailing of self-registration forms to those with handicapped driver registrations, a form could be provided at the time of application. The keys to an effective identification are creativity and matching the level of proposed record cost to the resources available and the desired effectiveness to the types of persons who need to be identified.

The five methods had different levels of record cost for each identified person with special needs with all data verified and address geocoded, ranging from \$50 for the saturation mailing to \$350 for the referral. The methods also had different level of effectiveness, ranging from moderate for mailings and to high for agency and support provider lists. Record costs can be reduced through the use of in-house staff and modifications to the methods employed for this study. The most cost-effective method was the use of lists acquired from various agencies and organizations, for these contained names and addresses of persons already recognized as having special needs. Table 1 summarizes the number of individuals identified as having special needs, regardless of whether they needed assistance, using each of the five methods.

A public information campaign was simultaneously conducted to encourage response by reaching critical target audiences in an understandable way through standard tools and approaches. It was critical to explain the purpose of the identification and how the results may lead to improved emergency planning and protective actions, especially for those with special needs; increase the understanding of individual responsibilities and protective actions in the event of a chemical release;

Table 1. Number of Individuals with Special Needs Identified by Various Methods

<i>Method</i>	<i>Individuals Identified</i>
Initial Random Sample	233
Saturation Mailing	1,750
Targeted Distribution	445
List Acquisition	
Support Provider Lists	878
Handicapped Driver Registrations	869
Referrals	904
<i>TOTAL</i>	5,079

and encourage IRZ households and special-needs populations to respond. In addition, twice-run half-page newspaper advertisements were run in ten daily and weekly newspapers serving the area.

In implementing these methods, special effort was directed toward gaining all persons' trust by assuring them that their privacy would be respected. All individuals were informed that "This information is being gathered under the authority of the State of Alabama, for the purpose of planning an emergency response. The State of Alabama will protect your privacy and all private information you provide." This wording was purposely composed to trigger the legal protections available to respondents from the Alabama Public Records Law. Confidentiality and data security procedures were developed and implemented to minimize the chances of confidentiality breaches.

Random-Sample Survey. A 10 percent random-sample survey of the estimated 31,000 households in the IRZ was conducted by the University of Alabama at Birmingham (UAB) to establish a base case estimate of the number of persons with special needs within the IRZ. Of the 2,640 households surveyed, half of the phone numbers were

extracted from a random selection of residential addresses. These addresses were obtained from a commercially purchased occupant data set. The remaining half of the telephone numbers was derived using a random phone number generator that replaced the last two digits of IRZ area phone numbers with two randomized digits. The latter method attempted to account for unlisted phone numbers and households that recently relocated to the area, as well as occupant lists often not having a phone number to accompany an address. The gross sample size of 4,328 cases was reduced to 3,159 after the exclusion of businesses, faxes, and nonfunctioning numbers. Using this method, 2,640 households were sampled. Households contacted were asked questions by interviewers using a computer-assisted telephone survey system and, as needed, in-person visits. The random sample survey method identified 233 persons with special needs within these households (approximately 9 percent of the sample). Referrals to other possible persons with special needs were requested during each interview.

Saturation Mailing of Self-Registration Packets. A total of 44,431 self-registration packets containing a self-registration form, registration instructions, a letter from the AEMA Director stressing the importance of self-registering, and a postage-paid return envelope were mailed to each household and mailbox in the IRZ. This mailing included all mailboxes along rural delivery routes that traverse the IRZ and even meandering outside the boundary, both business and residential addresses. It also included all post office boxes (although only 20 percent were considered residential). This accounts for the difference between the number of residences (31,000) and the number of packets mailed (44,431). The saturation mailing resulted in self-identification of approximately 1,750 persons with special needs.

Targeted Distribution of Self-Registration Packets. Support-service and housing organizations were provided self-registration packets to distribute to their constituents. Using these support groups to target packet distribution ensured a high probability of reaching those with special needs, through such means as the public paratransit system, public housing authorities, senior citizen centers, public and private health or social service agencies, volunteer organizations, schools, and religious institutions. Information regarding the registration packet distribution was often included in organization newsletters. Using this method, 445 persons returned completed registration forms identifying themselves as having special needs.

List Acquisition. Lists of potential individuals with special needs were acquired from public and private sources that have the greatest

opportunity to interact directly with possible persons with special needs. These sources included support providers and caregivers; community, neighborhood, and religious leaders; school teachers and school administrators; medical facilities; and service agencies, organizations, and associations. These sources provided 39 lists that yielded 878 names of potential persons with special needs. Mailings were targeted to persons on these lists. Handicapped driver license plate and placard records provided an additional 1,500 names. This number was reduced to 869 after accounting for multiple vehicle registrations, successive renewals by existing registrants, and persons having a general delivery or post office address and no telephone number.

Referrals. Based on sociological research methods involving social and personal networks and acquaintanceships (Kochen 1989; Bernard, Johnsen, and Killworth 1991), a referral technique, described as a "chain referral" system or "snowballing," sought to identify hidden people with special needs by asking those being interviewed to refer other individuals who might have special needs. Through this method, 904 referrals were received from 23 percent of the households contacted.

Establishing an Initial Special-Needs Population Database

As each special-needs household was identified, information regarding the individual was entered into a database. The completed database, compiled over a 16-month period, comprised 3,294 individual records of persons with special needs residing in 2,912 IRZ households. Because multiple identification methods were being employed simultaneously, duplicates were inevitable, so a "deconflicting" process was implemented, and 1,785 of the initial records (approximately 35 percent) were deleted as duplicates. Each set of duplicate records was merged into a single record before record deletion, with preference given to the data from the most recent record, except that all medical, transportation, and dependency (e.g., child alone) information was included on the merged records regardless of its age. This assured that the worst-case version of a respondent's special needs was included in the database. The process of deconflicting records was time consuming. Corrective measures included double-checking names, addresses, and telephone numbers during survey data collection and vetting records using telephone books, commercial residential address lists, address CD-ROMs, directories, Internet searches, and maps.

Lessons learned during the process of deconflicting were that name inconsistencies resulted because some people provided nicknames,

maiden or married names, and middle names in lieu of their first names on different forms. Names were misspelled during data entry either due to difficulties with handwriting or to problems with pronunciation during interviews. As a result, the names of some people were entered into the database two or more times.

An additional difficulty in successfully identifying and geocoding special-needs households was address problems, such as the misspellings of street names, nonexistent or incorrect directional prefixes (e.g., N, NW, NE, E, etc.) on street addresses, incorrect address ranges (often an omission or addition of a digit from the street address), incorrect street types (drive, street, avenue, or road), and Zip code errors (often the last digit was incorrect). Telephone numbers were often hard to decipher, or digits were inverted. These inaccuracies occurred whether the information was provided on a self-registration form, in a telephone interview, on a list, or in a referral.

Verifying and Updating the Special-Needs Population Data

As part of a data maintenance effort, each person with special needs received via mail a copy of the original data provided and was asked to verify its accuracy and update it, as needed. A cover letter explained how the special-needs information was collected, asked responders to review and correct the information they previously provided, and requested them to approve the withdrawal of their names from the database if they no longer required assistance from sources outside their family, friends, relatives, and neighbors. Two weeks after the verification mailing, a saturation mailing of self-registration packets was made to all IRZ households to allow new persons with special needs to identify themselves because they had recently moved into the community, were current residents who had changed circumstances, or had an increased awareness of the need to register. In addition, a weekly check of obituary pages in area newspapers led to the removal of records from the database.

Verifying Records

A butterfly form was designed for verifying and updating records. Each person's previously submitted personal information, physical and medical problems, and ability to take a protective action, along with a request to circle data that needed to be changed was printed on the left side. Respondents were asked to enter changes on the right side.

Corrected or verified forms were received from 1,548 (47 percent) of the originally identified special-needs population.

Some 296 (9 percent) of the verification packets were returned to the post office as undeliverable. Up to three telephone calls were made to those whose packets were not delivered, which resulted in address corrections and data verification for 133 individuals with special needs.

Of the remaining 1,450 verification forms that were not returned, a single telephone call led to successful contact with 427 individuals for data verification. In some instances, calls were made to nonresponders after a confirmation check with that person's list provider as to the person's situation. At the end of the verification process, 1,186 of initially identified persons with special needs had not verified their records by mail or had not been reached by telephone.

Of the 2,108 records verified by return mail or telephone contact, 208 persons requested that their information be removed from the database because they did not need assistance, 181 were identified as deceased, 49 had relocated outside the community, and 63 had entered nursing homes. A total of 1,601 persons with special needs (49 percent of the original records) confirmed by mail or telephone that they needed assistance in taking one or more protective actions.

A significant problem that had to be overcome during telephone interviews of nonresponders from this vulnerable population was their fragility. Interviewers had to be trained to exhibit great patience and understanding when conversing with those who had not returned their forms. These respondents offered reasons, often in an apologetic or contrite tone, for not returning the verification form during telephone calls. The majority stated they were not able to review, update, or mail back the form due to their own very debilitating physical or medical impairment (e.g., Parkinson's or Alzheimer's disease, crippling arthritis, or visual impairment). The next three reasons cited with equal frequency were: (1) recently returned home from a hospital, nursing home, or a family member's home after an illness; (2) a relative or neighbor who handles all correspondence did not get to it; and (3) did not get it done, even though they knew it was very important and meant to do it. Caretakers and guardians also said that they knew returning the form was a priority, but got too busy and forgot to do it.

Updating through Self-Registration

A year after the first saturation mailing, and concurrent with the verification effort, a second saturation mailing was carried out to identify

persons with special needs who had recently moved and existing residents whose situations may have changed. This second saturation mailing resulted in the return of 2,325 self-registration forms. After deconflicting records, an additional 1,090 persons with special needs in 985 households were identified as needing assistance. Nineteen returned envelopes did not contain a valid response. Concurrently, 356 persons returned self-registration and verification forms. Returns came from 274 households stating they had no children and therefore did not need assistance. Persons with physical and medical problems not needing evacuation or sheltering assistance outside the family or current circle of relatives, friends, and neighbors numbered 546. Also, 123 of the households resided outside the IRZ. Multiple names on forms resulted in 83 forms being divided into two or more records. A final verified and updated database of 2,691 respondent records was released to the Alabama CSEPP community.

Portrait of the IRZ Special-Needs Population

The purpose of the public safety survey sponsored by AEMA was to identify, to the greatest extent possible, those with special needs who would require assistance in taking one or more protective actions in case of an emergency at the depot. During UAB survey pretests and the identification initiative, opportunities existed to ask additional survey questions about an individual's personal situation and capabilities and attitudes related to emergency preparedness and response planning. The resulting data can be used to profile those persons with special needs who need assistance in taking specific protective actions.

Instruments Used for Data Collection

Data on the general and special-needs populations were collected using two data collection instruments—the self-registration form that was saturation-mailed and distributed through organizations, as well as a survey questionnaire. The survey questionnaires were conducted by mail (pretest), by an interviewer using a computer-assisted telephone survey system (random-sample and special-needs population surveys), and by an interviewer during an in-person visit (pretest, random-sample, and special-needs population surveys).

The self-registration form was composed of three basic sections. First, personal information was requested as to name, address, age, and phone number. Second, a checklist of possible problems was presented.

space was provided for accommodating additional information. Last, a set of five questions sought to determine their ability to evacuate, shelter, or implement a plan for a child home alone as protective actions.

The focuses of the random-sample survey and the special-population survey differed. The random-sample survey had nine sections, and while it contained most of the special-population survey questions, it also contained additional questions concerning the depot, public emergency preparedness, and family responses in the event of an accident. The special-population survey had four sections: attitudes and preparedness, impairments and protection alternatives, referrals to other persons with special needs, and respondent characteristics. On average, the surveys took an hour and twenty minutes to complete, due to questions seeking detailed information as well as referrals; some respondents' desire to talk significantly extended that time. Respondents during interviews appeared to report more incidences of Parkinson's and Alzheimer's diseases, mental capacity problems, and amputated limbs than with the use of a form. They also clarified their vision and hearing problems to interviewers.

A pretest questionnaire issued as a booklet with 24 questions was mailed to 637 households in the IRZ and the Protective Action Zone (PAZ) prior to the development of the self-registration form and the random-sample and special-population surveys; 503 responses were received. The purpose of the pretest was to test field methods and determine question viability, response return rate differences between the IRZ and PAZ (none), any bias in return addresses between UAB and a local post office box (none), and any response rate problems among age groups (none). Several questions that sought to understand the sense of community and type of responses to be generated were not used beyond the pretest, but the responses received are appropriate for building a profile of the special-needs population.

Simultaneously implementing two data collection instruments—a self-registration form and a survey questionnaire—revealed identification biases. The self-registration form provided personal distance from the self-identification process, whereas the survey required verbal interaction either by telephone or in person. Embarrassment about leaving children unattended may explain why the self-registration form identified a significantly larger number of children needing assistance because they were at home alone and persons who were transportation-dependent. During the survey process, people were asked to make referrals to other households with persons having physical or medical problems. Many did, but in the case of children possibly being home alone at times

or people not having transportation, few referrals were made, possibly due to an unwillingness to personally report these situations.

The two instruments also revealed data collection biases. The self-registration form offered respondents a choice between two answers—"yes" and "no." Survey forms relied extensively on scaled answers, allowing persons to provide equivocal responses that might not be acceptable to an emergency planner. The survey also allowed people the option of responding with "do not know" or an ambiguous response such as "so-so" or "maybe." The verification form, a version of the self-registration form, translated scaled answers into "yes" and "no" responses, then allowed respondents the opportunity to revise those interpreted answers.

Response Planning Characteristics

The data collected through the self-registration and survey instruments allow characterization of the special-needs population in the Alabama IRZ. Two response planning characteristics from this database—physical and medical problems and inability to implement specific protective actions—provide details necessary for emergency preparedness and response planning. The information that follows is derived from 3,091 surveys (94 percent of the special-needs population from the initial identification effort) and from analyzing information on self-registration forms.

Physical and Medical Problems. All respondents, through either the self-registration form or UAB interviews, were requested to detail any physical and medical problems by either checking boxes or responding to an interviewer's questions. People had a lot of discretion in making these personal and subjective choices as to whether their own situation could be characterized as "cannot see," "cannot walk," "cannot move," or another physical or medical problem category. Some checking the "cannot see" box could be blind, others might have severe glaucoma, and still others might have night blindness. In some cases, a guardian, parent, neighbor, relative, child, or other person might make that subjective decision for a person with special needs for whom they were completing a form or responding to an interviewer's questions.

Returned verification forms contained, on average, two and one-half physical and medical problems per person. Persons claiming to be mentally disabled or confused checked a larger number of boxes than those reporting only other special needs. Half of the forms included a self-described clarification or elaboration of a problem, which respon-

dents felt was vital to understanding their situation or problem. Self-descriptions contained explicit information as to the impairments, for example, the presence of Alzheimer's or Parkinson's disease, crippling arthritis, seizures, tumors, diabetes, or too overweight for a spouse to lift. Infrequent disabilities, but the most difficult with respect to protective actions, were also provided, such as quadriplegic, paraplegic, or on a feeding tube. Others provided situational information, such as not having a car, living alone, nobody near, or cannot drive.

Understanding the physical and medical needs of the special-needs population is essential to providing the necessary care, whether during an evacuation or in a reception center, mass care shelter, or their home. Persons might need replacement equipment or supplies soon after evacuating, such as oxygen tanks, special beds and chairs, wheelchairs, bedpans, catheters, and critical medications. Table 2 provides the percentages of reported physical and medical impairments.

The IRZ is in close proximity to an institute for the deaf and blind, which may affect the reporting frequency for those who cannot see or hear. Some persons checked the "physically unable" box on the self-registration form as a summary of their condition without explaining what the elements were.

Reported Ability to Implement Protective Actions. All 2,691 persons with special needs in the database, by definition, believe (or a caregiver believes) that they require assistance from outside the family or current circle of relatives, friends, and neighbors for one or more of the protective actions (evacuate, shelter, or implement a plan for a child home alone). Those who stated that they could not evacuate responded either (1) that the person with physical or medical problems or their family could not provide all the assistance needed to evacuate or (2) if a car were not available for them or their household, no family member, relative, neighbor, or friend could provide a ride. Separately, 60 percent reported that they did not have family assistance to evacuate, and 59 percent stated that they could not get a ride from friends, neighbors, or relatives if a car were not available. Those who stated they could not create an expedient shelter in their home responded that this could not be done by themselves or a family member, nor could assistance be expected from relatives, neighbors, or friends, if advised to do so by their county emergency management agency. Table 3 provides the percentages of the special-needs population reporting a need for outside assistance in taking one or more protective actions.

Table 2. Percentages of Persons with Special Needs Reporting Various Physical or Medical Problems

<i>Medical or Physical Problem</i>	<i>Percentage of Persons with Special Needs Reporting the Problem</i>
Cannot Drive	47
Cannot Walk Well	41
Problem with Heart	26
Problem with Back	25
Physically Unable	22
Vision Problem	18
Hearing Problem	18
Has Wheelchair	14
Is Confused	14
Mentally Disabled	8
On Oxygen	7
Is Bedridden	5
Cannot Move	3

Table 3. Type of Assistance Reportedly Required by Percentage of Special-Needs Population

<i>Assistance Required</i>	<i>Percentage of Special-Needs Population Reporting the Problem</i>
Cannot Shelter	62
Cannot Evacuate	44
Cannot Evacuate or Shelter	37
Child Alone with No Plan	8

In addition to those explicitly stating that they could not evacuate or shelter, some persons did not respond to this series of questions. A non-response in the case of sheltering might reflect a lack of knowledge of what is involved in creating a shelter environment at home. The 21 percent who did not reply as to whether they would need outside assistance in creating a shelter at home, and the 6 percent who did not indicate whether they could evacuate, were assumed to require assistance.

Portrait of Those Needing Assistance

A portrait of a special-needs population needing assistance was developed based on descriptive statistics (e.g., averages and frequency distributions) using data from two data sets. Within the 2,691 records, 1,203 persons had completed a lengthy survey form during the initial data collection. Each of these persons had physical and medical problems or was transportation-dependent and had recently verified the need for assistance from outside the family or a circle of relatives, friends, and neighbors in taking one or more protective actions. Additional profile information was derived from a small group of persons with special needs (39) who were interviewed as "referrals" during a field pretesting of survey instruments for the following 10 percent random-sample and movement-impaired surveys. Some of these pretest survey questions were later not incorporated in the final survey form. The sections that follow present the self-characterization of the special-needs population in the study community.

Personal Characteristics. The typical person with special needs needing assistance in the Alabama IRZ is an elderly woman, white, widowed or divorced, Protestant, continuing to live in a home she owns, who has a high school education, marginal income, and impairments lasting over five years. Women respondents outnumber men by two to one.

The special-needs population is elderly, as characterized by the majority (62 percent) being 70 years of age and older and 80 percent being 60 and older. There were 0.5 percent under 15 years of age. A slight majority has lost its marital partner (42 percent are widowed; 10 percent divorced), while 38 percent are still married.. They reside in houses (79 percent) as opposed to mobile homes (8 percent) or apartments, condos, or duplexes (13 percent); 80 percent own their own residence. As to religious preference, 86 percent were Protestant. The ethnicity of the population (76 percent white, 19 percent black or African-American) closely matches the 1990 U.S. Census data for the area (80 percent white, 19 percent black or African-American).

Almost half completed 12 years of schooling (with 43 percent of these having some college education); 42 percent have a ninth grade education or lower. Of the respondents reporting their incomes, 68 percent stated they had incomes of \$15,000 or less (almost half reported receiving federal assistance), and almost 25 percent reported incomes of \$30,000 or more. Few (5 percent) use a post office box for mail delivery, less than the 20 percent usage by area residences.

In the survey pretest, residential longevity was identified, with the majority having resided at their current address for 15 or more years, while 10 percent had a two-year or less residency. During pretesting, it was discovered that approximately a one-quarter of those with special needs live alone, and almost one-half have two persons in the household.

Guardians provided the survey information in 28 percent of the completed interviews. Guardians were partners by marriage, relatives, neighbors, or caregivers. Seventy-five percent of the guardians were women, over half of whom were 60 years of age or older (with 29 percent 70 years of age and older). Guardians generally had a higher level of education than their charges, as 63 percent had completed 12 years of schooling.

The vast majority reported they had had their impairments for an extended period of time. Table 4 provides the percentages of the population that reported the duration of their physical and medical impairments.

Table 4. Percentages of Special-Needs Population by Period of Impairment

<i>Length of Impairment</i>	<i>Percentage of Special-Needs Population</i>
Less Than 1 Year	4
1 Year	4
2 - 4 Years	25
5 - 10 Years	32
11-19 Years	11
20 -29 Years	12
30 Years or More	12

Almost 100 percent of residences reportedly had electricity. Answering questions regarding their ability to receive emergency instructions, 97 percent of the respondents reportedly had a telephone (31 percent had a cellular or digital phone), 80 percent had a radio, and 86 percent had television service using cable, 79 percent had service using an antenna, and 14 percent used a satellite dish. Close to 15 percent of the residences had computers, but the percentage connected to the Internet was unknown.

Community Involvement. The special-needs population in this study can generally be characterized as reportedly having some linkage to their community, such as attending church, having a strong attachment to their "home and place," and having at least a limited level of involvement in their community. A majority (57 percent) of persons with special needs reported attending church with some regularity, while 10 percent indicated they rarely attended. Of the 782 stating they attended church, only 17 did not name their religious affiliation. In the limited survey pretest, 36 percent claimed to be involved in their community, such as going to church, attending events, or participating in local elections, while 35 percent indicated they were not very involved, and 23 percent said they were not involved at all. Also, in the survey pretest, 70 percent claimed to be very much attached to their home and place, 11 percent claimed they were much attached, and 2 percent had no real attachment.

Implementing Protective Actions. Persons with special needs reported concern about an accident at the chemical weapons storage location, were pessimistic about their chances for survival, and would quickly attempt to implement any ordered protective action. They had a sense of distance, for most correctly placed themselves within the IRZ's outer boundary of 10 miles, with 11 percent stating they did not know the distance from their residence to the storage site and 15 percent providing a distance of greater than 11 miles. A majority (58 percent) were concerned about an accident at the storage site with chemical fumes escaping, while 12 percent were not concerned at all. As to the possibility of dying due to a chemical weapons accident no matter what they did for a protective action, 36 percent felt they would die, 34 percent were unsure or did not know, and 26 percent felt they would survive.

Most respondents seemed to understand the impacts of an emergency evacuation, because 88 percent expect roads to be jammed with traffic. Most agree (84 percent) that it is their duty to follow orders from local and state government officials in taking protective actions, while 4 percent disagree. Many (46 percent) agree that officials have devel-

oped workable emergency plans; 17 percent disagree, and 15 percent do not know. But, individual preparedness planning in the unlikely event of accident at the storage site is limited, because 62 percent have not discussed emergency planning information related to a chemical weapons accident with anyone, while 30 percent reported holding discussions with family members, 11 percent with neighbors and relatives, 9 percent with friends, and 0.5 percent with others.

When asked about taking a protective action, only 6 percent stated they would take no protective action. Meanwhile, a majority (52 percent) were at least somewhat confident about evacuation, although close to a majority (49 percent) were not very confident about sheltering at home to avoid dangerous fumes. As to evacuation, only seven persons were unwilling to evacuate, and 44 percent said they would not be able to evacuate. Regarding the in-place sheltering option, 66 percent agreed they would stay in a home shelter if directed to do so, though 62 percent indicated they cannot create a temporary shelter.

Five percent of those with physical and medical problems who would need assistance in taking a protective action had children who would be at home alone at times. Seven households purported to have plans in place for their children, although most of those plans consisted of going back home to assist their children.

Expectations of Assistance. Families play a critical role in providing assistance to evacuate and shelter those who need assistance in taking a protective action. Men (24 percent) were more definite than women (18 percent) in their expectations that the family would provide assistance in an evacuation. Women did not expect assistance in the creation of a protective home shelter (82 percent), whereas men were somewhat less negative (72 percent). Part of an explanation may be the large number of elderly women with no husbands (family). A measure of uncertainty exists in the expectation of assistance from the family, for respondents stated they were uncertain (probably and definitely) of the anticipated assistance with an evacuation (18 percent) or creation of a home shelter (34 percent).

An alternative to family assistance is assistance from a relative, neighbor, or friend. For assistance with a ride if a car were not available, expectation of a ride was equally split between relatives (37 percent) and neighbors (37 percent), and to a far lesser extent friends (13 percent). However, the rides were not definite; 60 percent of persons with special needs felt they could count on expected rides from relatives, 51 percent from neighbors, and 47 percent from friends. Assistance with the creation of a home shelter requires more of a com-

mitment, so relatives are key (38 percent), neighbors less so (25 percent), and friends even less (13 percent). For some, no assistance was expected from relatives, neighbors, or friends regarding a ride (24 percent) or creating a home shelter (25 percent). Few people expected assistance from combinations of relatives and friends (2 percent) or relatives, neighbors, and friends (6 percent).

Assessments of the certainty of receiving needed assistance in evacuating or sheltering differ among family members (husband and wife or parent and child) with special needs residing in the same household. For example, a wife (87 years old) portrayed a difficult household situation, stating that no family assistance was expected, no vehicle was available, and a ride was uncertain, whereas her husband (86 years old) reported the opposite. Similarly, a father (75 years old) reported no family assistance was expected, no vehicle was available, and a ride was uncertain, whereas his son (42 years old) reported the opposite.

Assistance Options for Those with Special Needs

When addressing providing assistance to populations with special needs with taking protective actions against natural, technological, and terrorism threats, written disaster plans must avoid creating an illusion of preparedness. Any operational planning effort should foster communication among emergency management agency planners, community leaders, persons with special needs, representatives of organizations and agencies involved with persons with special needs, and those with available resources. Proposed protective actions should consider designs that respond to both fast arriving (e.g., a HAZMAT release or a tornado) and more slowly developing threats (e.g., a hurricane or a flood). The nature of the threat (speed of arrival, type of hazard, size of the affected area) helps determine whether the assistance is put in place prior to the incident, is geared toward self-sufficiency, or is provided by outside sources during a response.

Like response planning, preparedness programs for special-needs populations have to be tied to training programs acceptable to the intended users, tied to the availability of necessary resources, and based on valid assumptions (Auf der Heide 1989). Every community has a great variety of facilities, skills, and resources available to handle many human service needs in the wake of a disaster that may be applied to providing protection assistance to special-needs populations before or during a hazard strike. There is also a need for a coordinated plan that links community resources together (California Governor's Office of

Emergency Services 2000), relies on community-based organizations that operate for purposes other than disasters (Tierney, Lindell, and Perry 2001), and fosters various forms of predisaster networking among community organizations (Gillespie et al. 1992). Such a plan must be available for the general population as well as for special-needs populations. Collaboration leads to the benefits of strength in diversity, expanded services, greater coordination, shared resources, and fewer service gaps (California Governor's Office of Emergency Services 2000).

Four categories of assistance in implementing protective actions need to be evaluated against a community's existing facilities, skills, and resources. First, education and training can increase self-sufficiency and decrease uncertainty about outside assistance. Second, a community-based support system could be developed based on expanding the robustness of established community or personal "lifelines" or networks. Third, a signal system that marks places of assistance or flags assistance could be devised to take advantage of community resources. Fourth, in-place support to facilitate taking a protective action could be achieved using technology placement and utilization.

Within each category are a combination of proven and innovative activities that could assist the entire population or various segments of it. Each category involves issues that need to be resolved before implementation. In some cases, a combination of options may be required to maximize the protection sought for those with special needs. In addition, a GIS-based software system can facilitate the delivery of assistance. Further empirical and practice-based research is essential to determining the viability of implementing various categories of assistance or combination of assistance.

Increased Self-Sufficiency. Educational and training materials using large type, diagrams, or Braille might be delivered to these persons or provided in outreach settings at various functions that explain how to increase the potential of securing a ride, using in-place equipment and materials, or constructing shelters with user-friendly materials and procedures. Training and personal instruction also can be offered at locations where persons with special needs receive social or medical services.

Community Support System. A community support system for taking protective actions can be activated by enhancing the use of personal buddies and promoting organizational adoptions. These can be built on established community or personal "lifelines" or networks, which allow a person with special needs to depend on others or community support services to function independently or perform daily activities. There must be surety that these services will not be cut or

dismissed in disaster situations. Support systems can be managed by a local government, volunteer organization, or professional facilitator and can be staffed by volunteers, paid staff, and/or paid recruits. Recruitment of support system members can be initiated through an aggressive public outreach program, sign-ups at county fairs or civic events, or targeted mailings. Confidentiality would be offered on various levels to both the special-needs person and the assistance provider, based on the wishes of the individuals involved.

If assistance were needed, a person with special needs would request a buddy, matched on the basis of location and ability, from a pool of volunteers or paid certified persons. At best, a single buddy could accommodate two special-needs households or possibly a maximum of three households; a buddy might be assigned to perform identification and support functions for persons with special needs living on a block or street. Each buddy would personally assist in arranging evacuation transportation and instruction on how to construct a home shelter environment. Buddies would have to develop a back-up of alternatives or substitutes, for at times they might not be available for a variety of reasons.

Religious institutions, service organizations (e.g., Jaycees, lodges and orders, posts, senior citizen centers, and Meals-on-Wheels), civic groups, and other entities (e.g., fire stations, schools, recreational teams, Scouts, hospitals, and garden clubs) can be recruited to adopt persons with special needs and participate in a community support system. They could specifically adopt their own members, past members, or those related to members who need assistance. Or, they could be assigned responsibility for one or more streets or blocks in proximity to their facility for the purpose of assisting persons with special needs in the vicinity. Individuals with special needs would then be informed that they could call one or more nearby organizations for assistance. Frequent calls could be made to check on the condition of those with special needs and to ensure that their assistance needs are being met. All could perform the adoption function either on a volunteer or paid basis to ensure an adequate response.

Signal Systems. Signal systems can be developed to take advantage of community resources. Signal systems could serve to notify persons with special needs of places where assistance is offered or to flag a person with special needs requiring assistance. Communication for assistance can originate from persons with special needs through pagers, TTY/TTDs, and cell links (donated cell phones preprogrammed to an emergency number or to persons with special needs through Reverse 911 and other avenues). An outdoor signal system (e.g., col-

ored lights, strobe lights, signs, and colored towels) could be designed so that relatives, neighbors, friends, and responders would be aware of a need for assistance and to foster spontaneity, enhanced through a public information campaign, so that random people passing by would know a household needed assistance to evacuate or establish shelter. A safe haven signal system (i.e., window placards) relying on approved households would signal to a child or person with special needs that evacuation or sheltering assistance is available there.

In-Place Support. In-place support technologies and delivery systems can be used to facilitate sheltering and, in some instances, evacuation. Technologies can involve such items as recirculating filters, personal protective gear (e.g., masks, protective hoods, bubble chambers, and air supply), sealants, and electronic sampling and monitoring equipment. Delivery systems can be designed for those with impairments, such as air infiltration minimization systems, whole-house filtration systems, foam sealant dispensers designed for those who cannot manipulate duct tape, and special sheltering kits with precut, adhesively prepared plastic window and door covers.

Issues in the Delivery of Assistance. Several critical issues need to be resolved in assisting those with special needs. As to the delivery of services, there are issues involving data confidentiality, guarantee of service, and potential liability of those involved. Appropriate care must be taken to ensure that volunteer "buddies" have cleared whatever local background checks or other precautions are appropriate to prevent criminals or other predators from using these systems to gain access to vulnerable residents. Assistance matching issues also involve data confidentiality as well as certifying the assistance provider has the physical abilities to provide the needed assistance, accommodating turnover both in support system members and persons with special needs, and extrication of system support members from personality clashes with persons with special needs. In addition, protocols must be established, such as log books, notification procedures, and family member involvement. Finally, ways must be found to provide assistance on a 24/7 basis that meets the expectations of both the persons with special needs and the members of a support system, as well as the dangers envisioned.

Conclusion

All households in a community, including those with a person with special needs, should develop an emergency preparedness plan for evacuation and sheltering in concert with the larger community preparedness

and emergency response plans. But there are households containing vulnerable individuals with extreme physical, medical, mental, or assistance needs who may require special planning and assistance with protective actions using a different assortment of protective strategies than for the general population. Although many of these persons with special needs are isolated from public view, the majority report a bond with their community. The identification and assistance process in response to a possible chemical weapons accident should be scrutinized as to its ability to be expanded to cover people with special needs encountering other possible emergency situations such as electrical outages and natural, technological, and terrorism disasters.

It is imperative to identify those special-needs households using a combination of data collection methods that are suited to the location, available resources, and community networks and linkages. Accuracy as to names, addresses, telephone numbers, and impairments is essential to being able to provide the assistance needed by each individual of the special-needs population. The data provided by each person are personal and subjective, while the data from the population as a whole are perishable, requiring constant aggressive maintenance, because a large percentage do not readily respond to update requests. Persons with a special-needs situation where assistance is needed appear to become more inclined to self-identify themselves after repeated outreach efforts and multiple mailings in this regard, although the reluctance of families and neighbors to report the presence of latchkey kids suggests that this special-needs group will require development of different approaches to increase identification success rates.

Emergency preparedness and response planning must incorporate active links to a coordinated, predisaster set of indigenous community-based resources to meet assistance needs. Options for helping those persons with special needs needing assistance must take into account all of the protective actions that might be required by officials and the speed and nature of the threat. These options include education and training for increased self-sufficiency, encouragement of a community support system, development of a signal system to take advantage of community resources, and in-place support. This new area of emergency planning will require multiple attempts at implementing combinations of these options and determining the ability of those in need to respond in ways that reflect sustainable disaster management action. All of these options can be applied to the larger special-needs population where vulnerability is a concern and community diligence is the practice.

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